RUNNING HEAD: LRD and LAD willingness

Knowing a donor and identifying as one: Determinants of people's willingness for related and anonymous living donation in Australia

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Abstract

While LRD (living donation to a genetically/emotionally related recipient) is well established in Australia, LAD (living anonymous donation to a stranger) is rare. Given the increasing use of LAD overseas, Australia may likely follow suit. Understanding the determinants of people's willingness for LAD is essential but infrequently studied in Australia. Consequently, we compared the determinants of people's LRD and LAD willingness, and assessed whether these determinants differed according to type of living donation. We surveyed 487 health students about their LRD and LAD willingness, attitudes, identity, prior experience with blood and organ donation, deceased donation preference, and demographics. We used Structural Equation Modelling (SEM) to identify the determinants of willingness for LRD and LAD and paired sample t-tests to examine differences in LRD and LAD attitudes, identity, and willingness. Mean differences in willingness (LRD 5.93, LAD 3.92), attitudes (LRD 6.43, LAD 5.53), and identity (LRD 5.69, LAD 3.58) were statistically significant. Revised SEM models provided a good fit to the data (LRD: χ^2 (41) = 67.67, p = 0.005, CFI = 0.96, RMSEA = 0.04; LAD: χ^2 (40) = 79.64, $p < 0.001$, CFI = 0.95, RMSEA = 0.05) and explained 45% and 54% of the variation in LRD and LAD willingness, respectively. Four common determinants of LRD and LAD willingness emerged: identity, attitude, past blood donation, and knowing a deceased donor. Religious affiliation and deceased donation preference predicted LAD willingness also. Identifying similarities and differences in these determinants can inform future efforts aimed at understanding people's LRD and LAD willingness and the evaluation of potential living donor motives. Notably, this study highlights the importance of people's identification as a living donor as a motive underlying their willingness to donate their organs while living.

The past decade has evidenced increasing acceptance of organ donations from living donors who are genetically or emotionally related (*living related donation* [LRD]) or unknown (*living anonymous donation* [LAD]) to the recipient as a means to meet the growing demand for organs worldwide (National Health and Medical Research Council [NHMRC], 2007). Programs for LRD in North America, Japan, and some European countries are well established (Henderson et al., 2003; Neuberger, Farber, Corrado, O'Dell, 2003; NHMRC, 2007) and several transplant centres in the United States have adopted LAD programs (Marks et al., 2006). In Australia, however, while LRDs have increased more rapidly than deceased donations (NHMRC, 2007), with the highest percentage of live donor kidney transplants ever recorded nationally (43%) in 2006, LAD is rare (only 7 non-directed kidney donations occurred in 2002-2006) (Campbell, McDonald, Chang, & Excell, 2007). The increasing use of LAD overseas and the creation of policy directives allowing LAD in some Australian states (e.g., New South Wales, Hambridge & Vamos, 2004), suggests it is likely that LAD will occur more frequently in Australia in the future (NHMRC, 2007) making an understanding of people's willingness and motivations for LAD essential. However, people's willingness and motivations for LAD in Australia has not been studied extensively. Furthermore, there is a paucity of research identifying the factors that explain large amounts of the variation in people's stated willingness to donate and the differences in LRD and LAD donor motives are unclear (Boulware et al., 2005).

Internationally, LRD is widely accepted by the general public with a reported 60% to 93% of people surveyed willing to donate (Landolt et al., 2001; Neuberger et al., 2003; Spital, 2001). People's enthusiasm for LAD is comparatively lower, with a reported 11% to 54% of people surveyed willing to donate (Henderson et al., 2003; Landolt et al., 2001; Spital, 2001). Motivations for LRD are self-evident and include the altruistic desire to help a loved one, seeing the outcome of the donation, moral or religious values, and family pressure

(Lennerling, Forsberg, & Nyberg, 2003). Motives for LAD, however, are less clear (Henderson et al., 2003) and it is often assumed that potential living anonymous donors must be psychologically unstable as they derive few benefits from LAD, have no emotional connection with the recipient, and receive no monetary compensation for their gift (Landolt et al., 2001). The possibility that living anonymous donors may have poor psychosocial outcomes as a result of psychiatric symptoms/disorders or other risk factors (e.g., unrealistic expectations about the outcomes of the donation process, expectation of secondary gain as a result of donation, unsuitable motives; see Dew, Jacobs, Jowsey, Hanto, Miller, & Delmonico, 2007) has led to transplant centres requiring rigorous psychological evaluation prior to acceptance as a donor (Boulware et al., 2005; Dew et al., 2007; NHMRC, 2007). Despite existing reservations, many living anonymous donors are psychologically stable and have legitimate motives for donation (Boulware et al., 2005). These LAD motives may include religious or spiritual values based on an organized religion (e.g., Christianity) or one's own internal belief system (Henderson et al., 2003), concurrent preference for organ donation upon death (Landolt et al., 2001; Popp et al., 2006), previous experience with organ donation (e.g., knowing a donor or transplant recipient) (Henderson et al., 2003; Rios et al., 2007), and having a history of volunteering or altruistic behaviours (e.g., donating blood) (Boulware et al., 2005; Dew et al., 2007; Henderson et al., 2003).

Another motivation that is alluded to in the living donation literature, but is not often studied, relates to the person having an identity as a donor (Piliavin, 1990). For many donors, LAD is an act that is consistent with their self concept or role as an altruistic person and serves as another opportunity to help someone in a life already exemplifying acts of philanthropy (Hambridge & Vamos, 2004; Henderson et al., 2003). Piliavin suggests that, if a person believes being an organ donor accords with their self-image, their willingness for donation will increase. In contrast, Borgida, Conner, and Manteufel (1992) argue that,

because kidney donation is a behaviour that cannot be repeatedly performed, individuals will not have the opportunity to develop a self concept or identity as a living donor and, therefore, identity-related factors will be less important when trying to understand people's motivations for living kidney donation. Although Borgida et al. are correct in their statement that identity is usually developed as a function of frequently repeated behaviour, we argue that an individual's notion of themselves as an altruistic person who performs charitable deeds is likely to inform their belief that they are the type of person who would donate an organ while living to a known person or a stranger (see Piliavin, 1990). We believe that, similar to a volunteer identity (Gargano, Nagy, & Rowe, 2004) or an organ donor identity (Hyde & White, 2009) informing deceased organ donation decisions, people can have a living donor identity that informs their LRD and LAD decision-making.

Given the importance of understanding donor motives for living donation, we compared the determinants of LRD and LAD willingness of students completing a health degree. We focused on students completing a health degree as an increase in LAD in Australia will mean that future health professionals, such as psychologists and nurses, may be involved in the assessment of donor motivations or the care of these donors and recipients. It is important for health professionals to be aware of their own motivations and the role that these motivations may play in the evaluation process. Specifically, we tested the impact of the determinants of: attitude, identity, deceased donation preference, previous organ donation experience (knowing a deceased donor, living donor, or transplant recipient or candidate), past blood donation, and religion, on people's LRD and LAD willingness. We examined also the differences in people's determinants of and willingness for each donation type.

Method

Participants and Procedure

Three hundred sixty five female and 122 male university students from Queensland, Australia, ranging in age from 17-65 years (M = 22.42 years, SD = 8.71 years) undertaking health related courses (e.g., psychology, nursing) participated in the study. Table 1 presents detailed demographic characteristics of the sample. Upon receipt of ethical approval from the University Research Ethics board, students were recruited via in-class announcements and received course credit and entry into a prize draw of four AUD$30 music store vouchers. Participants were assured of the voluntary, anonymous, and confidential nature of participation and provided informed consent. Sixty-one percent of the respondents approached initially completed questions related to their LRD and LAD willingness, attitudes, identity, previous blood and organ donation experience, deceased organ donation preference, and demographics.

Measures

Willingness. One item measured LRD and LAD willingness: "I am willing to donate an organ/part of an organ while living to a partner or family member (a stranger)", scored 1 *strongly disagree* to 7 *strongly agree*.

Attitude. Four, 7-point semantic differential format items measured LRD and LAD attitude: "For me to donate an organ/part of an organ to a partner or family member (a stranger) while living would be": *good-bad*, *worthless-valuable, negative-positive, favourable-unfavourable*. The four items were averaged to form reliable LRD (α = .88) and LAD (α = .90) attitude scales.

Identity. One item measured LRD and LAD identity: "I am the type of person who would donate an organ/part of an organ while living to a partner or family member (a stranger)", scored 1 *completely false* to 7 *completely true*.

Donation experiences. One item assessed respondents' prior blood donation experience: "Have you donated blood/blood products in the past?". Experience with organ

donation was assessed with three items: “Have you personally known anyone who was an organ/tissue donor upon their death?”, “Have you personally known anyone who donated an organ/part of an organ while living?”, and “Do you know anyone who has had an organ/tissue transplant or is on an organ transplant waiting list/register. Respondents’ preference for deceased organ donation was assessed with one item: “Do you wish to be an organ donor in the event of your death?” All items were coded 0 *no* and 1 *yes* for analyses.

Demographic items. Respondents’ demographic characteristics were recorded with their age in years, gender (1 *male* and 2 *female*), ethnicity (1 *Caucasian* and 2 *not Caucasian*), and affiliation with an organised religion (0 *not religious/no formal religion* and 1 *religious affiliation*) all measured.

Results

Differences in Attitudes, Identity, and Willingness for LRD and LAD

The majority of respondents held a positive attitude toward LRD (91%), perceived themselves as the type of person who would be a living related donor (68%), and were willing to donate while living to a genetically or emotionally related recipient (87%) (Table 2). Respondents mostly viewed LAD positively (71%), but fewer respondents believed themselves to be the type of person who would be a living anonymous donor (19%), and fewer people reported being willing to donate anonymously to a stranger (37%) (Table 2). Paired sample t-tests showed that the mean differences in LRD and LAD attitudes, identity, and willingness were significant (Table 3).

Determinants of Willingness for LRD and LAD

We used Structural Equation Modelling (SEM) via AMOS 6.0 to identify the predictors of people’s LRD and LAD willingness. Seventeen cases with missing values were removed for analyses, leaving a total of 470 respondents. Maximum likelihood was used to estimate the parameters of the model. Model fit was determined by the following indicators:

chi-square test (non-significant or acceptable if no more than 3 times the degrees of freedom) (Kline, 2005), Comparative Fit Index (CFI > 0.90), Tucker-Lewis Index (TLI > 0.90), and Root Mean Square Error of Approximation (RMSEA < 0.08) (Marsh, Balla, Hau, 1996). Path coefficients and R^2 values were also inspected to evaluate the predictive power of the model. Using SEM for each separate LRD and LAD situation, we tested the impact of attitude, identity, deceased donation preference, previous organ donation experience (knowing a deceased donor, living donor, or transplant recipient/candidate), past blood donation, and religious affiliation, in predicting people's donation willingness. In each model, we assessed the influence of relevant demographics (age, gender, and ethnicity) and allowed attitude and identity to co-vary.

The initial models for LRD (χ^2 (54) = 292.24, $p < 0.001$, CFI = 0.62, TLI = 0.53, RMSEA = 0.10) and LAD (χ^2 (54) = 324.01, $p < 0.001$, CFI = 0.64, TLI = 0.56, RMSEA = 0.10) willingness were not a good fit to the data. In both models, modification indices suggested that model fit would be improved significantly if the variables of knowing a deceased donor, living donor, and transplant recipient/candidate were allowed to co-vary amongst themselves, age was allowed to co-vary with past blood donation, knowing a living donor, and knowing a transplant recipient/candidate, and gender was allowed to co-vary with knowing a deceased donor. The LRD and LAD models were revised incorporating the suggested co-variances and additional paths suggested by modification indices (Figures 1 and 2) and provided a good fit to the data.

Revised LRD model. The revised LRD model (χ^2 (41) = 67.67, $p = 0.005$, CFI = 0.96, TLI = 0.93, RMSEA = 0.04) incorporating paths significant at least a the $p < 0.05$ level revealed: past blood donation and gender informed deceased organ donation preference, religious affiliation and deceased organ donation preference informed LRD identity, ethnicity and deceased organ donation preference informed LRD attitude, and LRD attitude, LRD

identity, past blood donation, and knowing a deceased organ donor predicted willingness for LRD. Age, gender, ethnicity, religious affiliation, knowing a living donor, knowing a transplant recipient/candidate, and deceased organ donation preference did not predict LRD willingness. The revised model explained 45% of the variance in people's LRD willingness.

Revised LAD model. The revised LAD model (χ^2 (40) = 79.64, $p < 0.001$, CFI = 0.95, TLI = 0.91, RMSEA = 0.05) incorporating paths significant at least at the $p < 0.05$ level showed: past blood donation and gender informed deceased organ donation preference, religious affiliation and deceased organ donation preference informed LAD identity, gender, ethnicity, and deceased organ donation preference informed LAD attitude, and LAD attitude, LAD identity, ethnicity, religious affiliation, past blood donation, knowing a deceased organ donor, and deceased organ donation preference, predicted LAD willingness. Age, gender, knowing a living donor, and knowing a transplant recipient/candidate, did not predict LAD willingness. The revised model explained 54% of the variance in willingness for LAD.

Discussion

While LRD is well established in Australia, LAD is rare (NHMRC, 2007). Given the increasing use of LAD overseas, it is possible that Australia will follow suit, signifying that an understanding of people's motivations and willingness for LAD is an important issue for examination (Hambridge & Vamos, 2004; NHMRC, 2007). We compared the determinants of individuals' LRD and LAD willingness in a sample of future Australian health professionals, and assessed whether these motivations differed according to living donation type. Similar to several other surveys conducted internationally (Henderson et al., 2003; Neuberger et al., 2003; Spital, 2001), there was a significant difference in LRD and LAD willingness. Significant differences in attitudes and identity based on living donation scenario were evident also. Using SEM to understand the predictors of both living donation types, we explained approximately half of the variation in LRD (45%) and LAD (54%) willingness and

identified four key determinants common to both types of living donation: identity, attitude, past blood donation, and having known a deceased organ donor. Religious affiliation and a preference for deceased organ donation were additional determinants of LAD willingness. We review these similarities and differences and offer suggestions to increase people's LRD and LAD willingness.

Regardless of the living donation context, we found that a person's living donation identity and attitudes were the predictors accounting for the most variation (i.e., largest beta weights) in living donation willingness. Those who believed they were the type of person who would donate while living to a known or unknown recipient and had more positive LRD and LAD attitudes were more willing to donate. The finding of identity as the predictor with the largest beta weight suggests that focussing on developing a person's living donor identity may be worthwhile. Promoting religious affiliations as accepting of living donation and a preference for organ donation upon death as consistent with the altruistic act of living donation may be two approaches to foster the development of a living donor identity. In addition, encouraging people to perform one-off and repeated donor identity confirming behaviours, such as registering as a bone marrow donor, donating blood, recording their deceased donation wishes on a donor card or register, and communicating their deceased donation decision to others, may also help to strengthen or reinforce a person's living donor identity (Hyde & White, 2009; Piliavin, 1990; Terry, Hogg, & White, 1999).

Theoretically, the importance of identity in this study supports the assertion that the development of a person's concept of themselves as the type of person who would donate their organs while living is not reliant on the repeated performance of behaviour (see also Piliavin, 1990). In the living donation context at least, it appears that identity can be important for the individual considering living donation for the first time to a known or unknown recipient, suggesting that a person's self concept may have a strong impact on behaviour

initiation in the living donation context. The findings suggesting the importance of a living donation identity in the current study, however, should be interpreted in light of study limitations including the use of one item to measure the identity construct. Future research, then, should adopt a multiple-item measure to represent better the identity construct. Nevertheless, the strong influence of identity in this study suggests the need for future research using qualitative and quantitative methodologies to further our understanding of the construct and role of identity in the living donation, and potentially other, donation contexts.

Consistent with previous research (Boulware et al., 2005), prior donation experiences were important in determining living donation willingness, with those who reported donating blood in the past and knowing a posthumous donor (but not a living donor or transplant recipient) demonstrating higher LRD and LAD willingness. If LAD were to be actively promoted in the future, these findings suggest that blood donors may be a worthwhile group to target. Future research, however, may wish to confirm this finding using a measure of past blood donation reflecting the extent to which (i.e., number of times) people have donated blood in the past (rather than the limited dichotomous measure employed in the current study)[1] and consider people's performance of other altruistic or medical donation behaviours (e.g., volunteering, charitable donation, oocyte donation, bone marrow donation) and their influence on living donation willingness. The findings suggest also that families of deceased donors may be effective advocates for living donation, particularly LAD, given its similarity with deceased donation in allocating organs for transplantation to an unknown recipient. In partial support of previous research suggesting a relationship between wanting to be an organ donor upon death and willingness for living donation (Landolt et al., 2001; Popp et al., 2006), we found also that a preference for deceased organ donation determined people's LAD (but not LRD) willingness, and their LRD and LAD attitudes and identity. People who want to

donate their organs upon death may serve as an additional potential target group in the event that the general public was engaged to consider living donation in the future.

Religious values, either those values subscribed to by an organised religion or one's own internal spiritual beliefs, have been cited previously as a motivation for LRD and LAD (Henderson et al., 2003; Landolt et al., 2001). In this study, however, we found that belonging to an organised religion predicted people's LAD willingness only. Since religious affiliation informed people's LRD and LAD identity, as well as LAD willingness, it may be worthwhile emphasising the support and approval of religious groups by promoting the idea that most organised religions endorse organ donation as an altruistic act that is consistent with religious or moral values.

Demographic variables of age, gender, and ethnicity were assessed, also. Ethnicity (non-Caucasian) was the only demographic variable predicting willingness for LAD. None of the demographic variables predicted willingness for LRD. Ethnicity (Caucasian) predicted attitudes toward LRD and LAD, with gender (female) emerging as an additional predictor of LAD attitudes. Although demographic factors are important to consider in living donation decisions (Dew et al., 2007), these factors are not amenable to change and, consequently, were not a focus of this study. Additionally, as the sample was comprised of primarily female, Caucasian, and younger respondents, we had less confidence in any findings pointing to demographic differences. Future research should aim to recruit a greater representation of males, non-Caucasian, and middle-aged (i.e., people aged 35-49 years who may be the most likely to be faced with a living donation decision; Organ Procurement and Transplantation Network, 2009) respondents.

Overall, the findings of this study demonstrate that future Australian health professionals have similar motives for LRD and LAD to those of the general public reported in other studies (Henderson et al., 2003; Landolt et al., 2001; Popp et al., 2006). While this

study makes an important contribution to the literature by comparing the determinants of people's LRD and LAD willingness, additional limitations of the study deserve comment including the measure of willingness (rather than behaviour), the potential for those people who felt more positively about living donation to self-select into the study, and the use of students only as participants. Given that LAD is rare in Australia, we were restricted to examining willingness for LRD and LAD, rather than actual LRD and LAD behaviour. A measure of living donation willingness is appropriate in this context as it indicates a general openness to performing behaviour if the opportunity arises (Gibbons, Gerrard, Blanton, & Russell, 1998) and willingness (intention) can serve as a proxy for actual behaviour (Armitage & Conner, 2001). It should be acknowledged, however, that the current study is limited in its use of one item to measure the construct of willingness. Future research should adopt multiple-item measures of willingness and use scenarios that simulate real world living donation experiences to assess people's willingness (e.g., a family member or friend needing a kidney; see also Gibbons et al., 1998). Moreover, if Australian LAD programs are established, the determinants of people's LRD and LAD willingness and behaviour should be assessed with a broader sample of Australian health professionals and the general public.

In conclusion, this study adds to the growing body of research demonstrating that those willing to be living donors have positive attitudes toward donation, religious values consistent with donation, a history of blood donation, experience with organ donation/transplantation, and a desire to be an organ donor upon death. Notably, this study demonstrates the importance of a living donor identity for those people expressing a willingness for LRD and LAD. Overall, these findings suggest that, although due caution should be exercised, we can report some confidence in the motives of living donors, particularly living anonymous donors, as people who see donation as another opportunity in their life to help someone in need.

Footnote

1. It should be noted also that, in the clinical setting, the extent to which a potential donor has donated blood in the past (i.e., number of times) would be considered a more appropriate measure (reflecting an ongoing commitment to performing altruistic behaviours) rather than a dichotomous assessment of any past donation experience.

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Table 1

Demographic Characteristics of Participants and Experience with Donation

	Frequency	%
Study discipline		
Psychology	241	49
Nursing/Medical science	151	31
Nutrition/Dietetics	43	9
Human Movement	36	8
Public Health	16	3
Ethnicity		
Caucasian	385	79
Non Caucasian	96	20
Not specified	6	1
Religious affiliation (organised religion)		
Yes	337	69
No	150	31
Past blood donor		
Yes	120	25
No	367	75
Wish to be a deceased donor		
Yes	365	75
No	121	25
Knew a deceased donor		
Yes	85	18
No	402	82

Know a living donor		
Yes	45	9
No	442	91
Know a transplant recipient/candidate		
Yes	161	33
No	326	67

Table 2

Percentage of Responses to Questions about LRD and LAD Attitude, Identity, and Willingness

Construct	Response	LRD (%)	LAD (%)
Attitude toward donation	Very negative	1	2
	Negative	1	8
	Neutral	7	20
	Positive	32	42
	Very positive	59	28
Identity (being the type of person who would donate)	Completely false	2	16
	False	11	41
	Unsure	19	24
	True	48	16
	Completely true	20	3
Willingness for donation	Strongly disagree	1	10
	Disagree/Somewhat disagree	4	26
	Neither agree nor disagree	7	27
	Agree/Somewhat agree	43	31
	Strongly agree	44	6

Note. LRD = Living related donation. LAD = Living anonymous donation.

Table 3

Mean Scores and Standard Deviations for Measures of LRD and LAD Constructs

Measure	LRD *M* (*SD*)	LAD *M* (*SD*)	*t* value
Attitude	6.43 (0.96)	5.53 (1.34)	16.41***
Identity	5.69 (1.39)	3.58 (1.61)	27.86***
Willingness	5.93 (1.31)	3.92 (1.63)	26.26***

Note. ***$p < 0.001$.

LRD = Living related donation. LAD = Living anonymous donation.

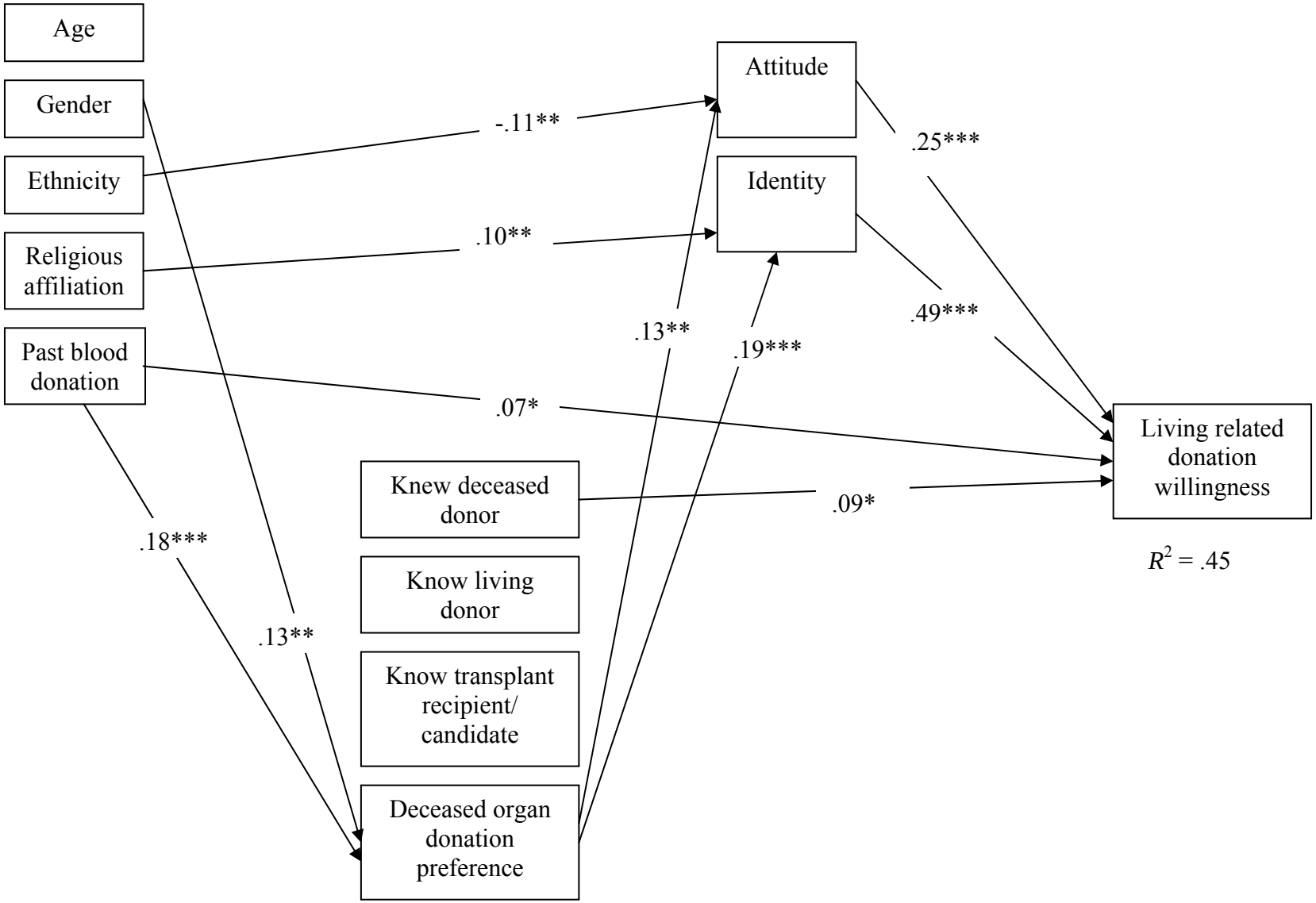

Figure 1. Revised living related donation model ($N = 470$). *$p < 0.05$; **$p < 0.01$, ***$p < 0.001$.

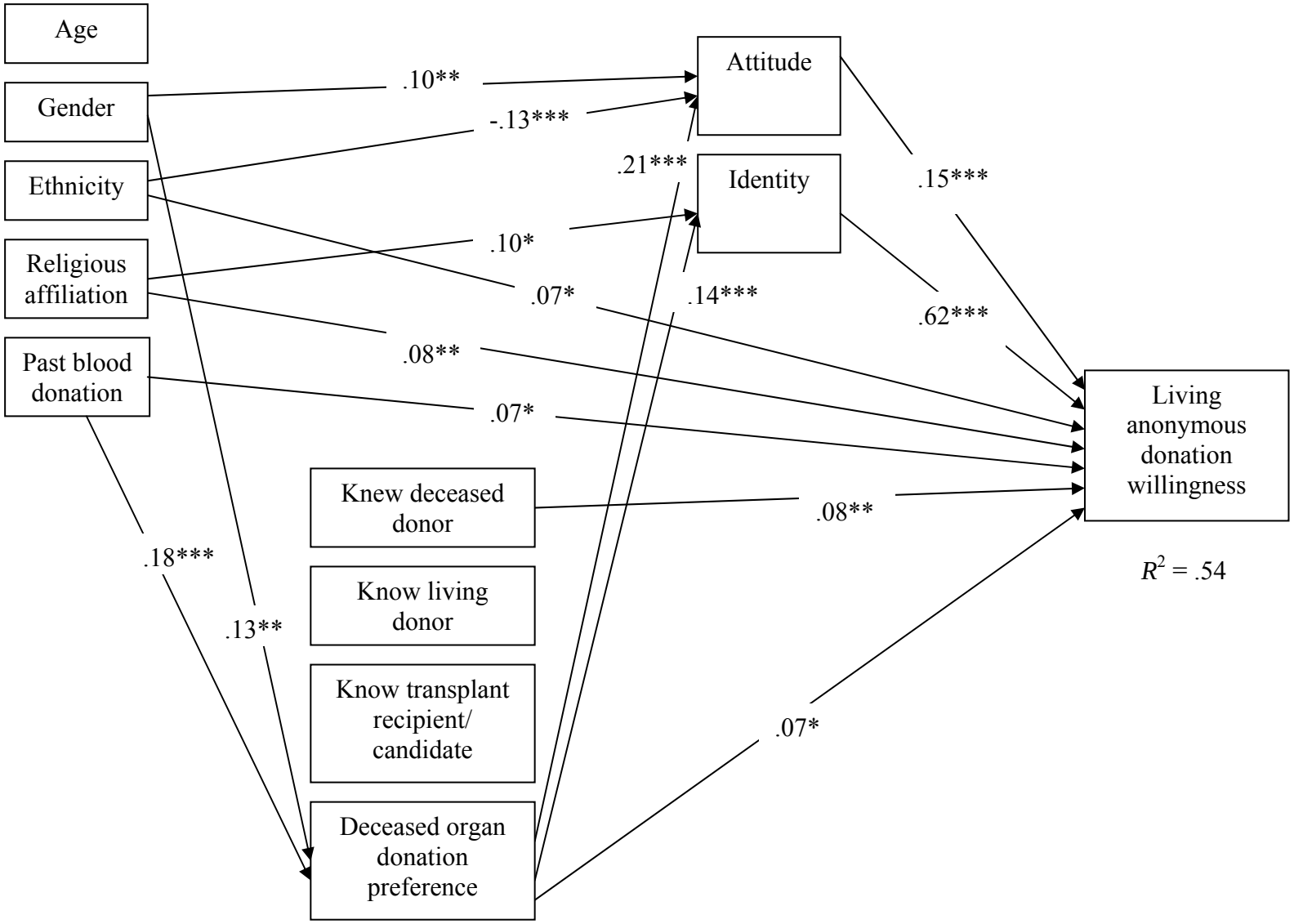

Figure 2. Revised living anonymous donation model ($N = 470$). *$p < 0.05$; **$p < 0.01$, ***$p < 0.001$.